

# NIH...Turning Discovery Into Health

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## Progress in Heart, Lung, and Blood Research

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### Congenital Heart Disease

The heart is the first organ to form and begin working in humans. More than two decades of research have told us a lot about normal heart development. New diagnostic tools such as fetal echocardiography now allow doctors to find heart defects during pregnancy. In 1950, a child born with a congenital heart defect had only a 20 percent chance of surviving. Today, most children who have complex heart defects survive to adulthood and can enjoy active, productive lives.

There are many types of congenital heart defects. Although gene mutations cause many of them, the causes of others remain unknown. One type of congenital heart defect, called tetralogy of Fallot, is the most common cause of “blue-baby syndrome.” Snowboarder Shaun White — who won Olympic gold medals in 2006 and 2010 — had surgery for this condition as an infant. He is a testament to the success of finding and fixing inborn heart defects early.

Many adults who survive congenital heart disease still face challenges. They are at higher risk for heart failure, pulmonary hypertension, fatal heart rhythm abnormalities, and other problems. Recognizing the importance of congenital heart disease as a chronic condition, the Pediatric Heart Network, funded by the National Heart, Lung, and Blood Institute (NHLBI), is following the health and outcomes of children with congenital heart disease over time to identify potential barriers in their transition to healthy adulthood.



Since it is now common for people with congenital heart disease to survive to adulthood, many ongoing NHLBI-funded studies are focused on ensuring further improvement in their quality of life as adults.

#### *Imagine the Future...*

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*Gene tests identify those at risk for future complications, so that people of all ages who live with congenital heart disease have personalized treatment plans – medicines, surgery, and lifestyle changes – tailored to their individual risk profiles.*

*Customized stem cells delivered before birth to fetuses with congenital heart defects grow into new heart valves or pumping chambers.*

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